

## A human right to shoes? Establishing rights and duties in the prevention and treatment of podoconiosis

Article (Published Version)

Shahvisi, Arianne, Meskele, Enguday and Davey, Gail (2018) A human right to shoes? Establishing rights and duties in the prevention and treatment of podoconiosis. *Health and Human Rights*, 20 (1). pp. 53-65. ISSN 2150-4113

This version is available from Sussex Research Online: <http://sro.sussex.ac.uk/id/eprint/75132/>

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

### **Copyright and reuse:**

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

# A Human Right to Shoes? Establishing Rights and Duties in the Prevention and Treatment of Podoconiosis

ARIANNE SHAHVISI, ENGUDAY MESKELE, AND GAIL DAVEY

## Abstract

Podoconiosis is a debilitating chronic swelling of the foot and lower leg caused by long-term exposure to irritant red volcanic clay soil in the highland regions of Africa, Central America, and India. In this paper, we consider the human rights violations that cause, and are caused by, podoconiosis in Ethiopia. Specifically, we discuss the way in which the right to an adequate basic standard of living is not met in endemic regions, where the following basic necessities are not readily available: appropriate footwear, health education, and affordable, accessible health care. Those living with podoconiosis experience disablement, stigma and discrimination, and mental distress, contributing to greater impoverishment and a reduced quality of life. We suggest that while identifying rights violations is key to characterizing the scale and nature of the problem, identifying duties is critical to eliminating podoconiosis. To this end, we describe the duties of the Ethiopian government, the international community, and those sourcing Ethiopian agricultural products in relation to promoting shoe-wearing, providing adequate health care, and improving health literacy.

---

ARIANNE SHAHVISI is a lecturer in ethics and medical humanities at Brighton and Sussex Medical School, Brighton, UK.

ENGUDAY MESKELE is a lecturer in human rights law at Wolaita Sodo University, Ethiopia.

GAIL DAVEY is a professor of global health epidemiology at Brighton and Sussex Centre for Global Health Research, Brighton, UK.

Please address correspondence to Gail Davey. Email: [g.davey@bsms.ac.uk](mailto:g.davey@bsms.ac.uk).

Competing interests: None declared.

Copyright © 2018 Shahvisi, Meskele, and Davey. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/3.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Background

Podoconiosis is a disabling and heavily stigmatized condition characterized by lower leg swelling (lymphedema) that, untreated, progresses to elephantiasis. It arises in genetically susceptible people who spend most of their lives barefoot and are thus exposed to clay soils found in tropical highlands.<sup>1</sup> Although the pathogenesis is not fully understood, soil particles penetrate the skin, are taken up by macrophage cells, and cause a chronic inflammatory process in the lymphatic system.<sup>2</sup> Lymphatic valvular dysfunction results in steadily progressive bilateral lymphedema, usually limited to below the knees.<sup>3</sup>

Globally, podoconiosis affects an estimated four million people, who live mainly in tropical Africa, Central and South America, and Southeast Asia. Recent mapping estimates suggest that there are 1.5 million people living with podoconiosis in Ethiopia and considerable numbers of affected people in Cameroon, Uganda, Rwanda, Burundi, and the Democratic Republic of Congo.<sup>4</sup> Podoconiosis has been reported in the Central American highlands in Mexico and Guatemala, as well as in Ecuador, Brazil, Suriname, and French Guiana in South America, but ongoing investigations suggest that few affected populations remain.<sup>5</sup> In Asia, podoconiosis has been reported in India, Sri Lanka, and Indonesia.

Although rarely a direct cause of mortality, podoconiosis disables those affected and leads to significant stigma within the community and health care settings.<sup>6</sup> Social stigma against people with podoconiosis leads to these individuals being excluded from school; denied participation in local meetings, churches, and mosques; and being barred from marrying unaffected individuals. Studies have documented low quality of life, mental distress, and depression.<sup>7</sup> Episodes of acute dermatolymphangioadenitis (“acute attacks”) are among the most severe clinical consequences of lymphedema, often confining individuals to bed while suffering malaise, fever, chills, lymphangitis, adenitis, and eventually skin peeling. These attacks occur frequently (reports vary from 5 to 23 episodes per year) and contribute substantially

to the disability and social impact associated with podoconiosis.<sup>8</sup>

Leg swelling and its consequences greatly reduce productivity, with affected individuals being half as productive as those with the same occupation but free of podoconiosis.<sup>9</sup> In one area of Ethiopia with 1.7 million residents, the annual economic cost of podoconiosis was more than US\$16 million in 2005—a figure that, when extrapolated to the country as a whole, suggests a cost of more than US\$200 million per annum.<sup>10</sup>

Despite the high impact of podoconiosis on rural farming communities in endemic countries, treatment and control are hampered by a range of issues. The key challenge faced is a general lack of awareness of the disease and the fact that it is different from lymphatic filariasis, the other main cause of lymphedema in the tropics. This lack of awareness is evident among health professionals, academics, and Ministry of Health staff. Podoconiosis-focused interventions are still so new that the challenges relate chiefly to program initiation rather than implementation. Fatalism is rife among health professionals in affected communities.<sup>11</sup> Where treatment is offered by small nongovernmental organizations (NGOs), issues such as distance, worries about stigma, illness, and misconceptions about treatment pose barriers to individuals’ continuing attendance for treatment.<sup>12</sup> These factors have led to an extreme neglect of individuals and communities affected by this debilitating disease.

## Introduction

Political and economic determinants are key to understanding the prevalence and epidemiology of any neglected tropical disease (NTD). Indeed, the category of NTDs is united not by biomedical commonalities but, as its name suggests, by commonalities of geographical distribution and neglect. This neglect has several components. NTDs are seriously under-funded, despite generally being inexpensive to treat. They and their treatments are also under-researched, especially in the pharmaceutical sector, as the populations they affect do not present opportunities for a return on investments.<sup>13</sup>

Relatedly, and perhaps most importantly, NTDs are under-represented in discourses on disease, mainly because they exclusively affect poor populations and therefore pose little threat to those in Global North contexts, but also because they are overshadowed by the “big three” diseases of the Global South: HIV/AIDS, malaria, and tuberculosis.<sup>14</sup>

It is therefore unsurprising that NTDs have received little attention in global health discussions, including in discussions of health and human rights. NTDs reveal the impact of structural factors on access to care and vulnerability to infection.

In this paper, we set aside the violation of the right to health in and of itself and instead turn to its constituent human rights violations. Unmanaged podoconiosis may be a violation of a person’s right to health, but it is more instructive to see it as a *symptom* of the fact that other rights have been violated and an indicator that still more rights *will* be violated. As Jonathan Mann et al. note, “[T]he extent to which human rights are realized may represent a better and more comprehensive index of well-being than traditional health status indicators.”<sup>15</sup> A major benefit of employing a rights discourse is that it centers on the *determinants* of health, allowing us to speak of entitlements to particular necessities rather than a vague, elusive entitlement to good health. And, of course, improving those determinants invariably has beneficial effects that extend beyond good health.

There are two ways of characterizing the interaction of podoconiosis with the human rights of those affected. The first concerns the way in which human rights violations contribute to podoconiosis; the second concerns the way in which podoconiosis then contributes to further human rights violations. The second set of violations may be seen as derivative of the first, but given that any strategy must address treatment as well as elimination, both are important.

Arguing that particular human rights have been denied is only the first part of the solution. Rights rely on a scaffold of duties for their realization. While rights generally apply to individuals and social groups, duties generally relate to agglomerate stakeholders in the form of governments and inter-

national organizations. In the case of podoconiosis, it is important to establish to whom the duties to provide treatments and efforts toward elimination fall. There are two ways of asking this question. One asks who is *responsible* for the well-being of those affected by the disease; this is a normative question. Another asks who is able to easily provide the necessary resources; this is a pragmatic question.

In the interest of maintaining a clear focus, this paper will consider podoconiosis in Ethiopia alone. This ought not to result in a significant loss of generality, since many of the rights violations in Ethiopia are also applicable in other endemic regions.

This article is structured as follows: in the first section, we describe the determinants of podoconiosis, including inadequate shoe-wearing practices, low health literacy, and the remoteness and inadequacy of health facilities. The following section then describes the ways in which podoconiosis leads to a series of additional human rights violations, mainly in the form of restricted health and employment possibilities, as well as stigma and discrimination. The final section explores strategies for improved treatment and elimination and identifies duty-holders in the achievement of these aims.

## Determinants of podoconiosis as human rights violations

Those living with podoconiosis are unable to realize their right to those basic necessities that are essential for reaching a standard of living that is adequate for health and well-being. This is despite the fact that low-cost, effective methods of prevention and treatment have been widely noted. In principle, podoconiosis is not a difficult disease to manage or eliminate: it occurs only in select geographies, it is not communicable, it is easily managed if spotted early, it is acquired only through long-term exposure to irritant soils, and its prevention requires neither pharmaceuticals nor large-scale infrastructural changes. Yet in practice, a series of complex, interrelated determinants collaborate to produce prodigious barriers to effective treatment and eventual elimination. Further, because podoconiosis is

not transmissible and tends to result in morbidity rather than mortality, it has been treated as a low priority.<sup>16</sup> As such, podoconiosis has been described as the most neglected tropical disease.<sup>17</sup>

The determinants of podoconiosis violate various human rights instruments. For example, article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which Ethiopia has ratified, recognizes the “right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing.”<sup>18</sup> Here, we understand that “adequate ... clothing” must be taken to include footwear, where its absence results in an inadequate standard of living. This closely parallels article 25 of the Universal Declaration of Human Rights, which states that “[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.”<sup>19</sup>

In addition, article 7(b) of the ICESCR enshrines the right to “safe and healthy working conditions” as a key realizer of the right to work.<sup>20</sup> This is important in the case of podoconiosis, since the majority of those affected by the disease are farmers working barefoot on irritant soils.<sup>21</sup> The African Charter on Human and Peoples’ Rights, which Ethiopia has also ratified, likewise calls for the right to work under “satisfactory conditions” (article 15).<sup>22</sup>

Article 16 of the African Charter on Human and Peoples’ Rights asserts the right to “enjoy the best attainable state of physical and mental health,” for which the state should “take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”<sup>23</sup> Similarly, article 12 of the ICESCR recognizes each person’s right to “the highest attainable standard of physical and mental health,” which is to be achieved by attending to

3. [t]he creation of conditions which would assure to all medical service and medical attention in the event of sickness.<sup>24</sup>

According to the Committee on Economic, Social and Cultural Rights, in order to realize the right to health, states are required to ensure that health care is available, accessible (physically, economically, and informationally, as well as without discrimination), of an acceptable ethical standard and with due regard to local cultural needs, and of good quality.<sup>25</sup>

It is clear that in Ethiopia, violations of the aforementioned articles contribute to the development of the disease. As described below, such human rights violations stem from a lack of suitable footwear for work and leisure, as well as resources for maintenance of good foot hygiene (for example, soap, water, bandages, and socks); inadequate health literacy; and inaccessible medical care.

### *Footwear and foot hygiene*

Podoconiosis has been eliminated in endemic regions of North Africa and Europe due to the widespread adoption of shoe-wearing, which is a powerful demonstration of the effectiveness of this single behavioral change. Like many “tropical” diseases, podoconiosis is tropical only in its current instantiation; it was once noted at latitudes as high as Scotland.<sup>26</sup> It is soil type, rather than climate, that is necessary for the development of the disease. That it is now endemic *only* in tropical regions is testament to the poverty of those regions. So while the cause of podoconiosis is geochemical, the reasons for its persistence are economic, cultural, and political.

In endemic regions of rural Northern Ethiopia, there is limited adherence to shoe-wearing. Foremost among the reasons for this is poverty, with families prioritizing nutrition and education for children above buying shoes. Those who can afford to buy shoes are often not able to replace them when they wear out. Since affordability is key, these shoes are likely to be of low-quality materials and workmanship, which tends to limit their durability, comfort, and suitability for manual work, as well as their degree of coverage, which is correlated with the protection they offer from irritant soils. This

1. [t]he improvement of all aspects of environmental and industrial hygiene;
2. [t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases; [and]

leads to inconsistent shoe use, as shoes are made to last by being worn only intermittently or for special occasions.<sup>27</sup> Gender disparities have been reported in the quality of footwear, with fewer women wearing the more expensive leather shoes that offer better protection.<sup>28</sup>

Once swelling sets in due to podoconiosis, it becomes difficult to find shoes that accommodate the larger foot size and shape. Standard footwear is often inappropriate, and affected individuals often rely on bespoke shoes designed and distributed by a few NGOs. However, these shoes are easily identifiable, which can lead to stigma and an aversion to shoe-wearing.<sup>29</sup>

Indeed, stigma plays an important role, with almost one-third of those affected refraining from wearing shoes in order to avoid being singled out.<sup>30</sup> In some cases, any variety of shoes, along with bandages or visible emollient use, is taken as a marker of disease or disease susceptibility—as a result, avoiding shoe-wearing may be a way of averting possible discrimination.<sup>31</sup>

A number of other practical concerns are relevant. A single pair of shoes worn continually in a warm climate without socks causes an unpleasant smell, which also leads to irregular shoe use, as people attempt to recurrently air their feet. Socks are therefore important in ensuring more comprehensive and comfortable shoe wearing. Furthermore, within podoconiosis-prevalent communities, clean water and soap are not always easily accessible, making foot hygiene difficult to maintain.<sup>32</sup>

In addition to shoe-wearing, household floor coverings are an important mechanism for minimizing foot-soil contact and thereby guarding against the development of podoconiosis. The lack of mats and cemented floors is common in endemic regions, largely because the importance of floor coverings is not well known and because covering household floors presents another expense.<sup>33</sup>

### *Health literacy*

Misconceptions concerning the causes of podoconiosis and preventative behaviors are common within endemic communities.<sup>34</sup> Various symbolic explanatory models for the disease circulate within

such communities, including the idea of podoconiosis as a form of religious punishment or a result of “magic,” often believed to be caused by stepping on dead animals.<sup>35</sup> In addition to posing barriers to preventing onset of the disease, these beliefs can lead to affected individuals seeking treatments from symbolic healers, which not only is costly and ineffective but sometimes leads to individuals being advised against attending podoconiosis clinics.<sup>36</sup>

Non-symbolic misconceptions also abound. There is the mistaken yet widespread belief that podoconiosis is infectious, which, coupled with the above symbolic beliefs, leads to considerable stigma around the disease. Other misnomers include the idea that the disease is transmitted by insects, by blood, or by affected individuals.<sup>37</sup> One study showed that only 41.4% of a podoconiosis-endemic community knew that the disease could be treated.<sup>38</sup>

Health literacy in relation to podoconiosis within endemic communities is low, with the average disease knowledge among women only half that among men.<sup>39</sup> Given that women’s beliefs are typically more determinative of children’s beliefs and behaviors, the effects of low health literacy in women are particularly concerning.

### *Health care*

Misconceptions among health professionals regarding podoconiosis are high, with one study reporting that 98% of respondents were ill informed about the causes of podoconiosis.<sup>40</sup> More than half believed that it was transmitted by insects, and half believed it to be infectious. Stigma toward affected individuals was high, and 86% of health professionals surveyed did not feel competent to treat the disease.<sup>41</sup> Further, 70% of the same group of health professionals reported lacking the basic resources (such as emollients and bandages) to provide treatment. Clearly, health care is held back as a result of inadequacies in both training and resources.

Even where health care is available, rural areas face barriers related to accessibility, with affected individuals citing distance from clinics and the need to meet other commitments (such as caregiving and other labor) as major reasons for discontinuing attendance.<sup>42</sup> Some individuals must



travel long distances by foot to reach clinics, which is physically challenging, while others rely on public transport, which is financially challenging. Those who live particularly far from clinics are also often deterred by the cost of an overnight stay.<sup>43</sup>

## The effects of podoconiosis on human rights

Podoconiosis has a major impact on affected individuals' enjoyment of human rights. Human rights are interrelated and interdependent, meaning that the violation of one right generally entails the violation of others. Neglecting the health vulnerabilities of those in disease-endemic regions eventually hampers social and economic opportunities and leads to further vulnerability.

Research conducted in endemic communities reveals that podoconiosis confers social, psychological, and economic burdens on affected individuals.<sup>44</sup> These individuals also experience absenteeism and reduced working hours due to frequent disease-related acute attacks.<sup>45</sup> Podoconiosis therefore poses a considerable threat to education and employment opportunities. In this section, we discuss how the disease can lead to the violation of three human rights in particular: the right to education, the right to work, and freedom from discrimination.

### *The right to education*

Article 13 of the ICESCR requires that primary and secondary education be "available and accessible to all by every appropriate means."<sup>46</sup> Those living with podoconiosis are deprived of this right on various fronts. They often have limited access to education due to disease-related acute attacks and due to stigma and discrimination. Disease-related acute attacks have a serious impact on school enrollment and completion, in addition to affecting attendance and performance. According to a recent study, pupils with podoconiosis may lose a considerable number of school days, drop out, underperform, and lack concentration as result of disease-related illness.<sup>47</sup> Schools in endemic rural areas are often located in remote villages, requiring students to walk long dis-

tances on foot, which is especially difficult because of the disabling effects of podoconiosis.

Moreover, students with podoconiosis often experience isolation, discrimination, verbal abuse, and harassment by peers within educational settings, leading their school attendance to fall.<sup>48</sup> Coupled with financial constraints, physical inaccessibility, and disease-related discomfort, stigma and discrimination pose major barriers to enjoyment of the right to education.

Although individuals with podoconiosis may appear to have the same notional access to education as unaffected individuals, the conjunction of these factors produces serious inequity. A particularly concerning byproduct of the lower level of education experienced by affected individuals is the effect on their health literacy and the ability to effectively manage the condition.

### *The right to work*

The right to work is essential for realizing other human rights and is a core source of personal development, as well as a facilitator of economic and social inclusion. The ICESCR enshrines the right to work under articles 6, 7, and 8. Since podoconiosis is so often *caused* by labor in the form of barefoot agricultural work, it is particularly lamentable that the disease frequently threatens a person's ability to work, both through physical impairment and through the effect of discrimination. Those whose education is disrupted as a result of podoconiosis may also find themselves less able to work by virtue of lacking necessary skills. The right to work is therefore undermined via violations of the right to health care, the right to healthy working conditions, the right to education, and the right to adequate footwear.

Individuals with podoconiosis experience rights violations in relation to access to, or continuation of, employment, which may occur due to discrimination or disease-related complications. They are often denied job opportunities, unfairly dismissed, and mistreated in the workplace.<sup>49</sup> Mirroring their behavior in educational settings, some affected individuals avoid employment as a way of minimizing stigmatization.<sup>50</sup> In addition, many are

unable to work due to physical impairment related to both ongoing lymphedema and acute attacks.<sup>51</sup>

### *The right to protection from discrimination*

The right to protection from discrimination recognizes the effect of stigma and discrimination on the social and economic opportunities of individuals, and the resulting increase in vulnerability. Stigmatizing attitudes continue to delimit the social and economic well-being of individuals with podocoinosis. This stigma is largely a result of low health literacy within endemic populations, including among health workers. In this way, it may be traced to a violation of the right to accessible information with regard to health issues.

Studies have demonstrated that individuals with podocoinosis face stigma and discrimination in the public and private realms. Both felt stigma (perceived fear of actual stigma) and enacted stigma (including unfair dismissal or school dropout due to discrimination) have been documented.<sup>52</sup> Stigma toward affected individuals is often manifested through differential treatment at social events, isolation from the community, limited marriage prospects, reduced access to education, and limited job opportunities.<sup>53</sup>

### **Duties regarding treatment and elimination**

Articulating rights violations paves the way for the identification of duty-holders and recommendations in relation to those rights. This section describes some extant initiatives that have been successful in tackling podocoinosis, identifies duties that must be met in order to address human rights violations, and explores the rightful duty-holders.

### *Promising interventions*

In Ethiopia, NGOs currently play a key role in offsetting the aforementioned rights violations. The most prominent of these are International Orthodox Christian Charities, Action against Podocoinosis Association, the Ethiopian Catholic Secretariat Social and Development Commission, and Mossy Foot International.<sup>54</sup> These organizations offer

programs focused on lymphedema management, awareness raising, and shoe distribution. Through the provision of health care, health literacy campaigns, and footwear, they respond neatly to the key human rights violations we have identified. However, their resources are understandably limited and unpredictable, and their geographical coverage is incomplete.

One particularly promising initiative was developed by Mossy Foot International, in which people with podocoinosis who have been successfully instructed in the management of their own podocoinosis (via shoe-wearing and foot hygiene) are trained to act as “community podocoinosis agents” within their local communities, inducting others into effective management of the disease and leading awareness-raising sessions and clinics in public spaces.<sup>55</sup> This highly effective scheme has the benefit of being patient led, which promises greater cultural sensitivity and credibility. (Importantly, it also meets the ICESCR requirement that the right to health be met in a “culturally acceptable” manner.) Furthermore, by offering good-quality, tailored care in each community, the program prevents affected individuals from having to travel long distances to reach clinics. This program could arguably be made even more effective by engaging expert patients in bridging the divide between biomedical health care and traditional healing, which could have the dual effect of increasing adherence to clinic treatments and ensuring that traditional healers provide medically sound advice.<sup>56</sup>

Such a scheme can be successful at larger scales only if health professionals are themselves adequately educated and resourced to be able to diagnose and treat podocoinosis, as well as to promote positive health behaviors among high-risk patient groups. At present, podocoinosis-endemic regions are not only deprived of the necessary resources for prevention and management (shoes, water, soap, bandages, and emollients) but also critically deprived in an *epistemic* sense. These epistemic lacunae are common in both patients and health professionals, and they provide fertile ground for the misconceptions that undermine comprehensive shoe-wearing and that promote stigma. As we have



shown, this stigma is a substantial barrier to the right to education for affected children, which in turn limits the capacity for employment and health literacy of those living with the disease. This point cannot be overstated: barriers to childhood education impede the capacity to work and the capacity to curb the development of podoconiosis, both of which affect vulnerability to poverty and disease. While shoe-wearing will be the key to eliminating podoconiosis, one cannot expect the practice to become widespread and enduring if it is not founded on an improved understanding of the disease.

The key area that is ripe for intervention is increasing the accessibility of durable, comfortable, protective shoes. A recent study demonstrated that almost three-quarters of those surveyed in Northern Ethiopia were willing to pay for footwear.<sup>57</sup> For the quarter unwilling to pay for footwear, the most important factor was poverty. Kebede Deribe et al. suggest that subsidized shoe-distribution schemes may be effective in ensuring more comprehensive shoe-wearing.<sup>58</sup> In addition to working alongside public health efforts to promote increased health literacy and the importance of consistent shoe-wearing, these schemes must capitalize on recent shifts toward shoe-wearing as a sign of respectability and fashion, especially among younger people.<sup>59</sup> Given the increasing desire for shoes—and the fact that most people are willing to pay for them—there is clearly a need for affordable footwear, which must be treated as a public health priority rather than a mere market opportunity. One way of meeting this need within communities is to extend schemes so that individuals with podoconiosis are trained to produce suitable footwear for sale or distribution within their communities.<sup>60</sup> Another option is for governments to collaborate with shoe companies in order to fund subsidies.<sup>61</sup> Partnerships have been formed with justice-oriented companies such as TOMS, which currently provides a free pair of children's shoes for every pair purchased, or Oliberté, which manufactures its shoes within a fair trade certified factory in Ethiopia.

### *Identifying duties*

The following interlocking changes are necessary

for the realization of human rights that will facilitate the elimination of podoconiosis and minimize its effects on individuals living with the disease:

1. The right to health:
  - Rural communities should have access to affordable health care services within walking distance, either via the establishment of permanent local clinics or via the regular presence of mobile clinics.
  - All curricula for health professionals working in endemic areas should include training on the pathogenesis, identification, and treatment of podoconiosis, and the physical resources for treatment should be readily available.
  - Health professionals should be tasked with training expert patients and working with traditional healers in order to improve health literacy within endemic populations.
  - Federal and regional governments should create cross-sectoral opportunities to raise awareness about podoconiosis in the wider community, through, for example, the agricultural, education, and development sectors.
2. The right to adequate clothing, including footwear:
  - Comfortable, affordable, long-lasting, protective footwear should be readily available within endemic populations for people of all ages. Promoting shoe-wearing should be an important part of the training for health professionals recommended above.
3. The right to safe and healthy working conditions:
  - Podoconiosis should be seen as an occupational health priority within the farming sector. Adequate footwear should be provided to workers as a health and safety measure, and shoe-wearing should be enforced.

Besides addressing rights violations, these recommendations respond to the aims of the United Nations Sustainable Development Goals, which call for the

elimination of neglected tropical diseases, universal access to high-quality medical care, improvements in the financing and training of health professionals, and safe working environments for all.<sup>62</sup>

### *Identifying duty-holders*

At the outset of this paper, we drew a distinction between the normative question of who is *responsible* for the well-being of those affected by podoconiosis, and the pragmatic question of who is able to easily *facilitate* the necessary changes. While NGOs have thus far played an important role in podoconiosis management—particularly in developing innovative techniques for management—larger-scale, better-resourced efforts, based on more extensive data, will be needed in order to bring about elimination.

The primary duty for preventing human rights abuses and seeking elimination must lie with the government of Ethiopia, which has sovereignty over the nation's land, one-fifth of the soils of which can cause podoconiosis.<sup>63</sup> In this regard, it is critical to note that agriculture is the cornerstone of the Ethiopian economy, accounting for almost half of the gross domestic product and 80% of the workforce.<sup>64</sup> This productivity is accounted for partly by the tremendous fertility of the soil, which is due largely to its volcanic origins.<sup>65</sup> Coffee growing, which represents 41% of the country's export earnings and 15% of the population's livelihood, is particularly reliant on these fertile volcanic soils.<sup>66</sup> In other words, the principal cause of podoconiosis is also a principal contributor to the nation's economic viability. Many of those affected by podoconiosis are coffee farmers or live in coffee-producing regions.<sup>67</sup>

The political economy of soil in Ethiopia reveals an important moral link between the nation's economy, which is currently in a period of promising growth, and some of the country's most neglected populations. It seems problematic for the nation's economy to benefit so vastly from its agricultural sector, while those living within podoconiosis-endemic agricultural communities are unable to access a "standard of living adequate for ... health and well-being ..., including food, clothing, housing and medical care and neces-

sary social services."<sup>68</sup> Failing to provide adequate health care and access to footwear is tantamount to environmental classism, with the rural poor being tied—both culturally and economically—to the land that is harming them, without the means to prevent those easily avoidable harms.<sup>69</sup> In other words, the right to safe and healthy working conditions is being violated for specific sectors of the population, amounting to a stark violation of article 2(2) of the ICESCR, which repudiates discrimination based on "social origin, property, birth, or other status." This is also a pressing occupational health issue, which links back to the way in which podoconiosis affects the right to work.

Care models such as that currently used by Mossy Foot International are highly effective and could be scaled up in an attempt to eliminate podoconiosis, provided the requisite resources and data are made available. As the principal duty-holder, the government of Ethiopia must provide these missing links in order to prevent the violations of human rights that are enshrined in the instruments the state has ratified. Indeed, ratification entails an obligation to respect, protect, promote, and fulfil these rights, and while progressive realization is an acceptable interpretation of this obligation, it is not clear that any notable progression has been made in reducing reliance on NGOs in managing and reducing podoconiosis. While there is a cost to implementing the improvements described above in endemic areas, this must be weighed against the 45% of working days lost each year and the increased health care costs of non-adherence to inadequate care options.<sup>70</sup> Clearly, a rigorous, well-resourced, shoe-wearing campaign, coupled with podoconiosis-specific training for health care workers, will be more cost-effective than managing the needs of an otherwise growing number of affected individuals.

Of course, one cannot ignore the fact that Ethiopia's health care system is weak, with the capacity to provide care to only half of the population and with a disproportionate share of funding focused on curative health care for urban populations, to the detriment of public health measures for rural populations. Only 42% of those in rural areas have access to health care facilities within walking

distance. The right to health of rural populations is patently not met. Until recently, efforts to treat podoconiosis had been led solely by NGOs, which have recently partnered with the Ethiopian Ministry of Health and have advocated for the integration of podoconiosis into the National Master Plan for NTDs. This promises to introduce lymphedema management services into government clinics and improve staff training, but the scheme is under-resourced (and still reliant on external donations), and government health care facilities do not serve all endemic rural populations.<sup>71</sup> This is perhaps unsurprising, given that only 4.9% of Ethiopia's gross domestic product is spent on health care.<sup>72</sup>

The poverty of Ethiopia must be seen relative to the wealth of the Global North; specifically, the capacity to provide vital services to Ethiopian people is hamstrung by the requirement that the state prioritize servicing high-interest debt to external funders. Ethiopia has been implementing a structural adjustment program since 1992, resulting in a diminished public sector, under-resourced health care services, and a reliance on NGOs to make up the shortfall.<sup>73</sup> This is not to absolve the government of Ethiopia of its aforementioned human rights duties but to be realistic about its capacity to deliver on those duties in light of its unrelenting economic dues. Ethiopia is not necessarily able to set its own priorities within a global economy that is hostile to the health needs of its population. Yet as noted by the Committee on Economic, Social and Cultural Rights in its General Comment 14, "[I]nternational financial institutions, notably the World Bank and the International Monetary Fund, should pay greater attention to the protection of the right to health in their lending policies, credit agreements and structural adjustment programmes."<sup>74</sup>

Reforms to debt repayment in light of this consideration—or, more radically, some form of debt relief—may be the most robust way to advance Ethiopia's capacity to improve its health provision and devote the necessary resources to rural settings to tackle podoconiosis.

In addition to debt, Ethiopia has a considerable problem of illicit financial flows.<sup>75</sup> Much of this is due to trade mispricing, in which the sale

and purchase of goods take place at prices that do not match those of the market, facilitating tax avoidance, largely by multinational enterprises whose subsidiaries are distributed globally.<sup>76</sup> Curbing illicit financial flows by increased global tax transparency and accountability will be key to ensuring that nations like Ethiopia can stem the tide of capital flight and thereby finance initiatives for the improved health care, education, and specific resources (such as footwear) that are necessary to eliminate podoconiosis and prevent further losses, both economic and social. Given the way in which the soil *mobilizes* export products even as it *immobilizes* those who work on it and with it, perhaps one narratively coherent suggestion for funding the necessary public health improvements could be through export taxes on agricultural products.

An additional set of potential duty-holders may be identified by considering the beneficiaries of Ethiopia's agricultural products. Since podoconiosis is so often an occupational health issue, those situated on the product supply chain must be responsible, at least in part, for the well-being of farmers. Three of the world's wealthiest nations—Japan, Germany, and Saudi Arabia—are the leading importers of Ethiopian coffee, while prominent multinational brands such as Illy and Starbucks are major suppliers.<sup>77</sup> Global North consumers and suppliers should be conscious of the working conditions of Ethiopian coffee farmers, many of whom are at high risk of developing podoconiosis or are living and working with the disease. There is considerable potential for ethical consumerism to assist in the elimination of podoconiosis by requiring shoe-wearing among farmers and, crucially, by providing appropriate footwear. Many consumers would resist buying products whose farming disables workers. In the Global North, coffee (particularly premium varieties, such as those that are regionally trademarked within Ethiopia) has relatively inelastic demand, so that high prices (as a result of, say, providing footwear to workers) can easily be passed on to the consumer.<sup>78</sup> Similar arguments may be made about corporate and consumer responsibility with regard to other Ethiopian agricultural exports.

In a globalized world, there are also global responsibilities for global health issues, and podoconiosis should not be taken as an exception simply because of its geographical specificity, lack of mortality, and lack of transmissibility. If the government of Ethiopia (and the governments of other endemic regions) is to be successful in eliminating podoconiosis, it will require the assistance of other bodies. As Gorik Ooms and Rachel Hammonds point out, growing wealth inequality between nations determines the ability of states in the Global South to invest in health-related goods.<sup>79</sup> Since the determinants of NTDs are so interlinked and tend to overlap geographically in their endemic regions, tackling podoconiosis should be part of a multi-NTD strategy of improved health care and improved literacy.<sup>80</sup> This must be viewed as a global responsibility; it is not something Ethiopia can—or should be left to—address on its own.

## Conclusion

Podoconiosis is a disease that persists as the result of failures to provide the basic necessities required for its elimination. It is caused by inadequacies in access to appropriate footwear, resources for foot hygiene, health literacy, and health care. These constitute violations of the right to a standard of living adequate for health and well-being. Moreover, once podoconiosis has developed within an individual, further rights violations occur in the form of stigma and discrimination, as well as adverse effects on education, employment, and social participation.

Paul Farmer and Louise Ivers describe the quandary raised by easily eliminable diseases as the “dilemma of global health in the 21st century: finally, we have the tools for prevention and diagnosis and care; what we lack is an equity plan linked to a delivery system.”<sup>81</sup> In the case under consideration, the solution could not be simpler: comprehensive shoe-wearing would eliminate podoconiosis within a generation. Yet of course, the “right to shoes” is in fact a complex bricolage of other rights, and poverty currently undermines their joint realization.

Increased efforts toward health literacy and shoe-wearing initiatives will be critical to ensuring

enjoyment of the right to an adequate standard of living and the eventual elimination of podoconiosis, while improved access to health services is vital to those already living with the disease. Implementing these improvements is the duty of governments of endemic regions toward their own citizens—but without broader structural changes to, for example, stem illicit financial flows and liberate funds for health care, countries of the Global South cannot be expected to finance the robust public health measures needed. Podoconiosis may pose no health threats to those on safer ground, but a disease of poverty is also a disease of wealth, and there is a global duty to prioritize elimination and thereby secure the rights of those in endemic regions.

## References

1. E. Price, “The association of endemic elephantiasis of the lower legs in East Africa with soil derived from volcanic rocks,” *Transactions of the Royal Society of Tropical Medicine and Hygiene* (1976), pp. 288–295; F. Tekoa Ayele, A. Adeyemo, C. Financ, et al., “The HLA class II locus confers susceptibility to podoconiosis,” *New England Journal of Medicine* (2012), pp. 1200–1208.
2. G. Blundell, W. Henderson, and E. Price, “Soil particles in the tissues of the foot in endemic elephantiasis of the lower legs,” *Annals of Tropical Medicine and Parasitology* 83/4 (1989), pp. 381–385; E. Price, “The site of lymphatic blockade in endemic (non-filarial) elephantiasis of the lower legs,” *Journal of Tropical Medicine and Hygiene* 80 (1977), pp. 230–237.
3. E. Price, “The pathology of non-filarial elephantiasis of the lower legs,” *Transactions of the Royal Society of Tropical Medicine and Hygiene* (1972), pp. 150–159.
4. E. Price, *Podoconiosis: Non-filarial elephantiasis* (Oxford: Oxford Medical Publications, 1990); K. Deribe, J. Cano, E. Giorgi, et al., “Estimating the number of cases of podoconiosis in Ethiopia using geostatistical methods,” *Wellcome Open Research* (2017), p. 78; S. Wanji, N. Tendongfor, M. Esum, et al., “Elephantiasis of non-filarial origin (podoconiosis) in the highlands of north-western Cameroon,” *Annals of Tropical Medicine and Parasitology* 102/6 (2008), pp. 1–12; C. Kihembo, B. Masiira, W. Lali, et al., “Risk factors for podoconiosis: Kamwenge District, western Uganda, September 2015,” *American Journal of Tropical Medicine and Hygiene* (2017), pp. 1490–1496.
5. Price (1990, see note 4).
6. Wanji et al. (2008, see note 4); B. Yakob, K. Deribe, and G. Davey, “Health professionals’ attitudes and misconceptions regarding podoconiosis: Potential impact on



- integration of care in Southern Ethiopia,” *Transactions of the Royal Society of Tropical Medicine and Hygiene* (2010), pp. 42–47; B. Yakob, K. Deribe, and G. Davey, “High levels of misconceptions and stigma in a community highly endemic for podoconiosis in Southern Ethiopia,” *Transactions of the Royal Society of Tropical Medicine and Hygiene* 102 (2008), p. 439; A. Tora, G. Davey, and G. Tadele, “A qualitative study on stigma and coping strategies of patients with podoconiosis in Wolaita Zone, Southern Ethiopia,” *International Health* 3/3 (2011), pp. 176–181.
7. J. Bartlett, K. Deribe, A. Tamiru, et al., “Depression and disability in people with podoconiosis: A comparative cross-sectional study in rural Northern Ethiopia,” *International Health* (2015), pp. 124–131; L. Henok and G. Davey, “Validation of the Dermatology Life Quality Index among patients with podoconiosis in Southern Ethiopia,” *British Journal of Dermatology* 159 (2008), pp. 903–906; E. Mousley, K. Deribe, A. Tamiru, et al., “Mental distress and podocooniosis in Northern Ethiopia: A comparative cross-sectional study,” *International Health* 7/1 (2014), pp. 16–25.
  8. Bartlett et al. (see note 7); Y. Molla, S. Tomczyk, T. Amberbir, et al., “Podoconiosis in East and West Gojam Zones, Northern Ethiopia,” *PLoS Neglected Tropical Diseases* (2012), p. e1744; Y. Molla, S. Tomczyk, T. Amberbir, et al., “Patients’ perceptions of podoconiosis causes, prevention and consequences in East and West Gojam, Northern Ethiopia,” *BMC Public Health* (2012), p. 828; K. Bekele, K. Deribe, T. Amberbir, et al., “Burden assessment of podoconiosis in Wayu Tuka woreda, east Wollega zone, western Ethiopia: A community-based cross-sectional study,” *BMJ Open* 6 (2016), p. e012308.
  9. F. Tekola, D. H. Mariam, and G. Davey, “Economic costs of endemic non-filarial elephantiasis in Wolaita zone, Ethiopia,” *Tropical Medicine and International Health* (2006), pp. 1136–1144.
  10. Ibid.
  11. Yakob et al. (2010, see note 6).
  12. A. Tora, G. Davey, and G. Tadele, “Factors related to discontinued clinic attendance by patients with podoconiosis in Southern Ethiopia: A qualitative study,” *BMC Public Health* (2012), p. 902.
  13. M. Etherton, “The ethics of global research funding,” *Penn Bioethics Journal* (2015), pp. 17–22; P. Trouiller, P. Oliaro, E. Torreele, et al., “Drug development for neglected diseases: A deficient market and a public-health policy failure,” *Lancet* (2002), pp. 2188–2194.
  14. L. Manderson, J. Aaraard-Hansen, P. Allotey, et al., “Social research on neglected diseases of poverty: Continuing and emerging themes,” *PLoS Neglected Tropical Diseases* (2009), p. e332.
  15. J. Mann, L. Gostin, S. Ruskin, et al. *Health and human rights: A reader* (New York: Routledge, 1999).
  16. K. Deribe, B. Kebede, B. Mengistu, et al., “Podocooniosis in Ethiopia: From neglect to priority public health problem,” *Ethiopian Medical Journal* (2017), pp. 65–74.
  17. G. Davey, E. Gebrehanna, A. Adeyemo, et al., “Podoconiosis: A tropical model for gene-environment interactions?” *Transactions of the Royal Society of Tropical Medicine and Hygiene* 101 (2007), pp. 91–96.
  18. International Covenant on Economic, Social and Cultural Rights (ICESCR), G.A. Res 2200A (XXI) (1966).
  19. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), art. 25.
  20. ICESCR (see note 18).
  21. F. Tekola Ayele, A. Adeyemo, and C. N. Rotimi, “Using a ‘genomics tool’ to develop disease prevention strategy in a low-income setting: Lessons from the podoconiosis research project,” *Journal of Community Genetics* 3 (2012), p. 7.
  22. African Charter on Human and Peoples’ Rights, OAU Doc. CAB/LEG/67/3 rev. 5 (1981), art. 15.
  23. Ibid., art. 16.
  24. ICESCR (see note 18), art. 12.
  25. Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000).
  26. Price (1990, see note 4).
  27. Yakob et al. (2008, see note 6).
  28. G. Tsegay, A. Tamiru, T. Amberbir, et al., “Willingness to pay for footwear, and associated factors related to podoconiosis in Northern Ethiopia,” *International Health* (2016), pp. 345–353.
  29. D. Ayode, A. Tora, D. Farrell, et al., “Associations between causal beliefs and shoe wearing to prevent podoconiosis: A baseline study,” *American Journal of Tropical Medicine and Hygiene* (2016), pp. 1123–1128.
  30. Yakob et al. (2008, see note 6).
  31. G. Tsegay, M. Wubie, G. Degu, et al., “Barriers to access and re-attendance for treatment of podoconiosis: A qualitative study in Northern Ethiopia,” *International Health* (2014), pp. 285–292.
  32. K. Deribe, S. Brooker, R. Pullan, et al., “Epidemiology and individual, household and geographical risk factors of podoconiosis,” *American Journal of Hygiene and Tropical Medicine* (2015), pp. 148–158.
  33. Tora et al. (2011, see note 6).
  34. Yakob et al. (2008, see note 6); H. Banks, G. Tsegay, M. Wubie, et al. “Explanatory models, health-seeking behaviours and self-care practices of podoconiosis patients in Northern Ethiopia,” *PLoS Neglected Tropical Diseases* (2016), p. e0004878; A. Tora, H. Franklin, K. Deribe, et al., “Extent of podoconiosis-related stigma in Wolaita Zone, Southern Ethiopia: A cross-sectional study,” *Springer Plus* (2014), p. e647.
  35. Tsegay et al. (2014, see note 31); Banks et al. (see note 34).
  36. Tsegay et al. (2014, see note 31).
  37. Tora et al. (2011, see note 6); Banks et al. (see note 34).
  38. Yakob et al. (2008, see note 6).
  39. Ibid.



40. Yakob et al. (2010, see note 6).
41. Ibid.
42. Tsegay et al. (2014, see note 31).
43. Ibid.
44. Bartlett et al. (see note 7); Tekola et al. (2006, see note 9).
45. Molla (2012, see note 8); Bekele et al. (see note 8).
46. ICESCR (see note 18).
47. E. Meskele, *The right to education of children and young people living with podoconiosis*, MSc thesis (Addis Ababa University, 2015).
48. Ibid.
49. Tora et al. (2014, see note 34).
50. Tora et al. (2011, see note 6).
51. Molla (2012, see note 8).
52. K. Deribe, S. Tomczyk, E. Mousley, et al., "Stigma towards a neglected tropical disease: Felt and enacted stigma scores among podoconiosis patients in Northern Ethiopia," *BMC Public Health* (2013), p. e1178.
53. Ibid.; Tora et al. (2014, see note 34).
54. Deribe et al. (2017, see note 16).
55. G. Davey, "Podoconiosis: Let Ethiopia lead the way," *Ethiopian Journal of Health Development* (2008), pp. 1–2.
56. Tsegay et al. (2014, see note 31).
57. Tsegay et al. (2016, see note 28).
58. K. Deribe, S. Wanji, O. Shafi, et al., "Measuring elimination of podoconiosis, endemicity classifications, case definition and targets: An international Delphi exercise," *International Health* (2015), pp. 306–316.
59. D. Ayode, C. McBride, H. de Heer, et al., "A qualitative study exploring barriers related to use of footwear in rural highland Ethiopia: Implications for neglected tropical disease control," *PLoS Neglected Tropical Diseases* (2013), p. e2199.
60. F. Tekola, S. Bull, B. Farsides, et al., "Tailoring consent to context: Designing an appropriate consent process for a biomedical study in a low income setting," *PLoS Neglected Tropical Diseases* 3/7 (2009), p. e482.
61. K. Deribe, S. Wanji, O. Shafi, et al., "The feasibility of eliminating podoconiosis," *WHO Bulletin* (2015), pp. 712–718.
62. United Nations, *The Sustainable Development Goals report* (New York: United Nations, 2016).
63. K. Deribe, K. Meribo, T. Gebre, et al., "The burden of neglected tropical diseases in Ethiopia, and opportunities for integrated control and elimination," *Parasites and Vectors* (2012), p. e240.
64. International Monetary Fund, *The Federal Democratic Republic of Ethiopia: Selected issues* (Washington, DC: International Monetary Fund, 2016).
65. I. Scoones, *Dynamics and diversity: Soil fertility and farming livelihoods in Africa; Case studies from Ethiopia, Mali, and Zimbabwe* (London: Earthscan, 2010).
66. N. Petit, "Ethiopia's coffee sector: A bitter or better future?" *Journal of Agrarian Change* 7/2 (2007), pp. 225–263.
67. G. Alemu, F. Tekola-Ayele, T. Daniel, et al., "Burden of podoconiosis in poor rural communities in Gulliso woreda, West Ethiopia," *PLoS Neglected Tropical Diseases* (2011), p. e1184.
68. UDHR (see note 19).
69. C. Gibbs and J. Melvin, "Structural disadvantage and the concentration of environmental hazards in school areas: A research note," *Crime, Law and Social Change* (2008), pp. 315–328.
70. Tekola et al. (2006, see note 9).
71. Deribe et al. (2017, see note 16).
72. World Health Organization, *Countries: Ethiopia* (2018). Available at <http://www.who.int/countries/eth/en>.
73. P. Krishnan, T. Gebre Selassie, and S. Dercon, "The urban labour market during structural adjustment: Ethiopia 1990–1997," *CSAE Working Paper Series* (1998). Available at <https://ideas.repec.org/p/csa/wpaper/1998-09.html>.
74. Committee on Economic, Social and Cultural Rights (see note 25).
75. United Nations Development Programme, *Illicit financial flows from the least developed countries: 1990–2008* (New York: United Nations Development Programme, 2011).
76. G. Brock and T. Pogge, "Global tax justice and global justice," *Moral Philosophy and Politics* (2014), pp. 1–15.
77. Petit (see note 66).
78. J. McDuling, *How Starbucks can raise prices for your coffee and get away with it* (2014). Available at <https://qz.com/237809/starbucks-can-raise-prices-for-your-coffee-and-get-away-with-it>.
79. G. Ooms and R. Hammond, "Taking up Daniel's challenge: The case for global health justice," *Health and Human Rights* (2010), pp. 29–46; B. Milanovic, *Worlds apart: Measuring international and global inequity* (New Jersey: Princeton University Press, 2011).
80. D. Molyneux, P. Hotez, and A. Fenwick, "Rapid-impact interventions: How a policy of integrated control for Africa's neglected tropical diseases could benefit the poor," *PLoS Medicine* (2005), p. e336.
81. P. Farmer and L. Ivers, "Cholera in Haiti: The equity agenda and the future of tropical medicine," *American Journal of Tropical Medicine and Hygiene* (2012), pp. 7–8.

